

chapter 7



planning for the long term

alzheimer's  association™

the compassion to care, the leadership to conquer

Over time, people with Alzheimer's disease lose the ability to manage their personal and financial affairs. Getting an early diagnosis, before your loved one's mental competency is in question, allows you and your family the most options in planning in advance for this loss. Some of this planning can be quite simple, while other planning options are more complicated and may require the advice of an attorney. When a person is not diagnosed in the earliest stages, he or she isn't able to plan in advance for the loss of their capabilities, and legal guardianship may be the only remaining option. The options below are presented in order of likely usefulness, from those that require the most competency, to those that require a legal determination of mental incompetence.

Joint Bank Accounts

A joint bank account is probably the most common and useful tool for people who need help managing their financial affairs. A joint bank account is any account that is owned by more than one person. Each joint owner has access to the entire account. When one owner dies, the funds pass directly to the other owner(s) without legal review or probate. Banks and other financial institutions usually have specific forms for setting up joint accounts.

An individual must have enough mental capacity to set up a joint account. Once the joint account is established, any joint owner can do whatever he or she wants with the funds in the account, even though

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Putting financial plans in place is important for everyone, but settling legal and financial matters is especially vital for the person with dementia.

his or her reasoning ability and judgment may have diminished over time. A joint owner can help an incapacitated co-owner with his or her financial or personal affairs by using funds in the account to pay rent, mortgage, taxes, utility bills, and to purchase clothes, food, and medicine.

Even though setting up a joint account is simple, you should consult with an attorney before pursuing this option with any relative needing care. Adding your name to a bank account could have significant consequences for you and for your loved one. It might jeopardize your loved one's eligibility for Medicaid or it might make you liable for debts incurred by the other joint owner. The Alzheimer's Association of Vermont can refer you to agencies that can help you find a lawyer who can advise you.

Durable Power of Attorney (DPOA)

It is important to distinguish between a Power of Attorney (POA) and a Durable Power of Attorney (DPOA). A POA is a written legal document by which one person, the "principal," appoints an "agent" to act on his or her behalf. The principal must always have the mental capacity to appoint and direct this agent. The agent's power to act on the principal's behalf automatically ends when the principal becomes incapacitated or dies. A Power of Attorney is not a very useful tool for individuals with Alzheimer's and their caregivers or "agents" because the progression of the disease always leads to mental incapacitation and the automatic end of the agreement.

A Durable Power of Attorney is a special kind of POA. It is durable because it does not automatically end when the principal becomes incapacitated. As a result, unlike the traditional POA, it can be a very effective planning device for people with Alzheimer's and their caregivers. However, like the regular Power of Attorney, the principal must be competent at the time the DPOA document is drawn up and put into effect.

The DPOA may be the simplest and least expensive long-term planning device for you and your loved one in early-stage Alzheimer's. Your loved

one can choose who will act as his or her agent and define the extent of the agent's powers. For a DPOA to be effective, the person granting the durable power of attorney usually gives his or her agent fairly broad authority to manage personal and financial affairs. Decisions concerning health care issues should be addressed through a living will or a separate Durable Power of Attorney for Health Care.

Once again, you and your family should seek legal advice when putting a DPOA into effect to make sure that the document is consistent with state law.

Trusts

A trust is a legal arrangement whereby a person or “grantor” transfers



money or property to a “trustee.” It usually requires the longest advanced planning of the options presented here. The trustee can be a person (such as a family member or an attorney) or an organization (such as a bank or foundation). The grantor must be mentally competent at the time the trust is established and the trustee is named. The trustee is required to manage the property in the trust for the benefit of the grantor and any other person or group named as a beneficiary in the trust document. The trust document may give the trustee very general, or

very specific instructions on how to spend and invest the trust property.

Trusts are important planning tools because they allow trustees to manage property on behalf of individuals who can no longer manage it for themselves.

It is important to seek legal advice before setting up a trust. The lawyer should be familiar with trusts and with Medicaid law and other public

assistance programs because being the beneficiary of a trust could affect an individual's eligibility for Medicaid, Supplemental Security Income (SSI) or other public benefits. The Alzheimer's Association of Vermont can refer you to agencies that will help you find a lawyer who can advise you.

Representative Payee

Becoming a "representative payee" means receiving certain federal payments on your loved one's behalf. At least five federal agencies (Social Security Administration, Department of Veterans Affairs, Department of Defense, Railroad Retirement Board, and the Office of Personnel Management) that administer different benefit programs will issue checks to representative payees if they determine that the person who should be receiving the payments is unable to manage the benefits due to physical or mental impairments. The representative payee is required to use the funds for the benefit of the original recipient, and the agency administering the benefit may monitor your performance and request an accounting.

One distinct advantage to representative payment is that it is available even when your loved one doesn't have the capacity to take advantage of other planning options, such as setting up a joint bank account or establishing a Durable Power of Attorney (DPOA).

Voluntary Guardianship

Adults who want assistance managing their personal and financial affairs can file a voluntary guardianship petition in probate court. The court must find that the individual is not mentally ill or mentally retarded. The court must determine that the person seeking a guardian understands the nature and consequences of the guardianship. Voluntary guardianship is not usually an option for individuals with Alzheimer's because by the time they need a guardian, they often are not able to understand what guardianship is and what it will mean for their lives.

If your loved one does not have enough capacity to understand voluntary guardianship, he or she should consider establishing a Durable Power of Attorney (DPOA) instead. The DPOA is generally a simpler, less expensive alternative that would also allow your loved one to choose a substitute decision maker and decide the extent of that person's authority.

Involuntary Guardianship

A guardian is appointed by a probate court judge to handle the affairs of another person (legally called "the ward"). Involuntary guardianship is the most far-reaching and restrictive option available to people who can no longer handle their own financial, legal, and medical affairs. A probate court judge can give a guardian the power to make all personal, financial, and medical decisions for the ward. Involuntary guardianship completely restricts the ward's ability to make decisions about his or her affairs.

Any interested individual may ask the probate court to appoint a guardian for someone else. You do this by filing a petition for involuntary guardianship with the probate court. The court clerk's offices have all the necessary forms. The judge will appoint a guardian if he or she finds that the person named in the petition is mentally ill or mentally retarded and cannot manage any or all of his or her personal or financial affairs. There is no special guardianship category for people with Alzheimer's, so the illness falls within the guardianship statute's definition of "mental illness," even though it is not otherwise considered to be a mental illness in the common use of that term.

Once a judge determines that an individual is mentally ill or mentally delayed, he or she can appoint either a total or a limited guardian. A total guardian has the power to make all decisions for the ward. A limited guardian may make only the decisions that the judge finds that the ward cannot make for him or herself. In either case, the guardian is responsible for making decisions that are in the best interests of the ward. The guardian should remain informed of the ward's needs and should involve the ward as much as possible in the decision making process. Some

decisions, like moving the ward from his or her home to a nursing home or residential care home, selling the ward's property and consenting to non-emergency medical procedures, require the permission of the court.

Planning Is the Key

The real key to maintaining the best possible quality of life for a loved one with Alzheimer's disease or another dementia is planning. Get a diagnosis as soon as possible, then consider how to face the future and take care of



yourself and your loved one financially. Get legal advice and ask questions until you understand all the implications of decisions regarding your financial options and obligations. If your loved one is able to participate in these decisions, he or she will feel less like something is being taken away and more like a responsible partner when he or she is included. Of course, the person with

dementia's feelings of anger and denial about the diagnosis may limit his or her ability to face the financial decisions that must be made. Outside advice may help you make clear why these decisions are necessary now.

Elder Abuse

Abuse, neglect, or exploitation of an elderly or disabled adult is against the law. Human service and health care professionals are required by law to report any abuse they witness or suspect. Family, friends and other individuals can report their concerns to Vermont's Adult Protective Services (APS) program (**1-800-564-1612**). Staff from this agency usually begin an investigation within 48 hours of a report of abuse or neglect. They will determine whether abuse, neglect or exploitation has occurred and decide whether a protective service plan is needed to ensure the victim is protected from any further abuse.

In addition to protecting the victim, these agencies may refer cases for either civil suits or criminal charges against any individual who is responsible for abuse, neglect or exploitation of an elder. Unfortunately, even when they never intended harm to their loved one, family members are sometimes responsible for such actions. It is important to recognize that one significant factor in abuse of an elder is caregiver stress.

The American Psychological Association (APA) has identified caregiver stress as one of the main risk factors for the abuse and/or neglect of an elder. The task of 24-hour-a-day caregiving takes its toll on even the strongest and most well-balanced of us. Caregiving for someone with Alzheimer's disease is demanding, frustrating work.

Any caregiver may feel helpless, trapped, socially and emotionally isolated and financially burdened at times, especially when a caregiver carries on without help. Remember, asking for help is a positive step you can take in caring for your family member as well as yourself!

Depending on what stage of the disease your loved one is in when he or she is diagnosed, and on his or her remaining abilities and needs, caregiving is likely to begin in your loved one's home or perhaps in yours. All caregivers need help from friends and family and/or from community-based services.

HOME-BASED CAREGIVING

Caring for a loved one with Alzheimer's can be a long-term proposition, adapting to a decline in abilities over years rather than a brief, intense health care crisis. As a caregiver, no matter how committed you are to helping your loved one, you will, at some point, need help from others. Help is essential to providing the best care for your loved one while maintaining your own health and well-being.

Sharing Responsibility with Friends and Family

Family and friends usually take a major role in providing care for a loved one with Alzheimer's. Often it falls to one particular family member to provide most of the care. He or she may live nearby, or has always had a caretaking role in the family, or has the most resources in terms of time or knowledge.

Encouraging others to become involved and remain involved throughout the illness helps them cope with their feelings about the disease by doing something and helps the primary caregiver by providing time for rest and rejuvenation. Call on your friends and family members – and those of your loved one – early in the process so they can learn as much as possible and make a good strong connection. You may even establish your own informal support group among caregiving friends and family to compare notes on your loved one’s abilities and the techniques that help to manage difficult times or decipher your loved one’s



attempts to communicate When your loved one spends time with, and becomes accustomed to other caregivers early on, it is much less stressful for everyone should a respite caregiver come in later. Having other family or friends involved in your loved one’s care also helps them overcome their own lack of information or fears about the illness and gives them an appreciation for your intensive role.

Sometimes friends and family seem to just melt away when a loved one is diagnosed with Alzheimer’s disease, and there are many reasons why they don’t help. Some may not feel as responsible because they aren’t as close to your loved one as you are. Some may not know their help is needed. They may not understand the nature of the disease and its effects; or they might not know how to offer help or what kind of help to offer. Some people may feel it would be tactless to imply that you need help or that your loved one is unable to function well anymore. Some may fear that helping would take too much time and would disrupt their own lives too much. Others might be frightened by the disease or by what they think your loved one might do

or say as a result of the dementia. Some don't want to be held responsible if your loved one wanders away or is injured while they are in charge.

One approach is to tell others what help you need (rather than waiting for an offer), and be specific. Identify small tasks and ask for assistance. Grocery shopping for you and your loved one (have a list prepared) can help a lot by removing one chore from your list. When your loved one is still moderately functional, even accompanying you and your loved one to the grocery store provides both of you with companionship and activity outside your home. People will often be glad to help when asked – especially when a specific task is to be done – even though they might never get around to offering on their own. It can be a lesson in warmth and humility to overcome your own sense of wanting to be the helper instead of the helped and to realize how many people sincerely want to be given the opportunity to help.

Community-based Services

Vermont offers many services that help you take care of your loved one in your home. These services can assist with some of the daily tasks and stress you may encounter. Eligibility is usually related to your loved one's functional abilities. Costs and fees vary and often depend on his or her financial circumstances.

Staff members at the Alzheimer's Association will refer you to agencies that will help you sort through the service options and funding resources. The following is a brief description, though by no means an exhaustive list, of possible community resources you might wish to consider (agencies, phone numbers, and websites are listed in the back of this book for your reference).

- **Attendant services** provide assistance with personal care, meal preparation, housekeeping, and more. In order to be eligible the person applying must have a physical disability.
- **Accessibility modifications** are changes in your loved one's home environment made for safety and accessibility, such as hand rails, grab bars in bathrooms, and wheelchair ramps.

- **Samaritan Connection**- Chittenden County Vermont only- assists with shopping, cooking, transportation, or provides a friendly social visit from a volunteer. Call (802) 654-1447.
- **Respite care** is available through several different programs. Families in Vermont may apply for a dementia respite grant; contact the Senior Helpline (1-800-642-5119) for information on the application process. Other programs, such as adult day centers, home health, senior companion, residential care, and nursing homes offer services that can allow you some respite.
- **Senior Companion** is a program that involves older volunteers who will visit with your loved one, play cards etc. on a weekly basis.
- **Senior centers** offer social, recreational and nutritional programs for the elderly.
- **Transportation services** are provided by different agencies and funding sources depending on the purpose for which the services are needed (shopping, trips to medical care, access to adult day centers, etc.). You and your loved one may use these services in the earlier stages of Alzheimer's. The Senior Helpline can provide information on local services.
- **Adult day centers** offer a caring environment for social interaction, physical activity, and intellectual stimulation for persons with a variety of care needs. Some centers have specialized programs for persons with dementia. Adult day center staff assist with personal care, medications and bathing. Some centers offer extended weekday hours and limited weekend hours. Many provide transportation. Your loved one can have the opportunity to interact with others in a protected environment, receive care from people other than the primary caregiver, and feel safe away from home. Having a regularly scheduled opportunity for respite is an important factor in your ability to continue caring for the person with dementia at home.

- **Support groups** can offer you, as a caregiver, the opportunity to share experiences, frustrations, ideas, issues, feelings, and problems and to ask questions with others who are caring for a person with dementia. You can get a list of local support groups from the Alzheimer's Association. You can also participate in on-line support groups over the Internet.
- **Safe Return** is a program of the Alzheimer's Association that provides identification for a person with Alzheimer's disease, and assistance in his or her return if he or she wanders away or becomes lost or confused.



The program is partnered with Medic Alert and applications are available on line at www.alz.org or through the Vermont Alzheimer's Association.

- **Home delivered meals/Meals on Wheels** provide one meal a day to frail and disabled homebound persons. The meals are prepared and delivered to your home. Contact the Senior Helpline at 1-800-642-5119 for information.
- **Homemaker services** assist with house-cleaning, laundry, shopping, and preparing meals. Contact your local Home Health Agency or Visiting Nurses Association.
- **Home Health aides** provide assistance with personal care and homemaker services. Contact your local Home Health Agency.
- **Home Health Agencies** can help your loved one when he or she has medical needs at home. Their staff includes nurses, aides, therapists, dietitians, and social workers. Your nearest Home Health Agency, senior service agency, Memory Disorders Center or your doctor can help you determine if your loved one qualifies for home health services. Services are provided only when a physician prescribes it.

- **Palliative Care** is provided by some Home Health Agencies to people with chronic, progressive illnesses such as Alzheimer’s disease and other disorders characterized by dementia while in their last stages of life. This service provides intermittent care at home with aides, nurses, and social workers, and shares the same general philosophy as hospice without the requirement that a person be in the final six months of life.
- **Hospice care** is the in-home physical, psychological, social, and spiritual care provided to the terminally ill, with a focus on pain management. Your doctor will help you determine if your loved one with dementia qualifies for hospice. Hospice services are usually reserved for the final six months of a person’s life.

OUT OF HOME CARE

Few of us want to think about putting a loved one “in a home” or in a long term care facility. You may be feeling that this discussion is coming way too early in this disease process, but there are at least four good reasons to think sooner, rather than later, about the eventual need for residential care: your loved one’s participation, your family’s comfort with a placement decision, your health, and your loved one’s safety.

Early discussions about the possibility of residential care or nursing home placement can give your loved one with dementia an opportunity to make his or her wishes known. It can also help everyone be more comfortable with this decision if and when the time comes. And in the later stages of Alzheimer’s disease, caregiving is not just a full time job, it is two or three full time jobs, around the clock. When the comfort and safety of your loved one is

Helpful Hints

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taken into consideration, as well as the stresses and strains on you as the primary caregiver, residential, or nursing home care may be the best option for everyone at some point.

CareFinder and Senior Housing Finder

CareFinder is a program of the Alzheimer's Association and is available online at www.alz.org/carefinder. Care Finder helps you easily and quickly find answers to your questions and guides you through care options designed for individual needs and preferences. Simply enter information about a person's needs, abilities and preferences, and the guide generates a private, customized printout with recommendations and questions to ask when screening a caregiver or a residential care facility.

The guide will also help families learn how to recognize good care, plan and pay for care and find local support. You can also use the Senior Housing Finder, www.alz.org/seniorhousingfinder to help find dementia care options in your community. In this program, you can obtain information about licenses residences throughout the US that offer services especially for people with dementia.

Types of Long Term Care Facilities

Vermont licenses residential care homes and nursing homes according to levels of care. Nursing services, medication management, general supervision, nursing oversight, and personal care services determine licensing rules and regulations.

Skilled Nursing Facilities (often called Nursing Homes)

Nursing homes are classified as Level I or Level II, and provide more medical management and oversight than do residential care homes. Residents of nursing homes require daily skilled nursing care, such as physical or respiratory therapy, the insertion and use of catheters, or intravenous

therapy. While the majority of nursing home residents are elderly, some are younger persons who may have a chronic condition, or who have recovered enough from surgeries, injuries, or illnesses to leave the hospital, but who cannot yet manage at home.

Alzheimer Special Care Units (SCUs)

SCUs are designed to meet the specific needs of individuals with Alzheimer's disease and other dementias. SCUs can take many forms and exist within various types of residential care. Such units most often are cluster settings in which persons with dementia are grouped together on a floor or a unit within a larger residential care facility.

Residential Care Homes are state licensed group living arrangements designed to meet needs of people who cannot live independently and usually do not require the type of care provided in a nursing home. When needed, help is provided with daily activities such as eating, walking, toileting, bathing and dressing. Residential care homes may provide nursing home level of care under certain conditions. Level III homes provide nursing oversight, but not full-time nursing care, while Level IV homes do not provide nursing oversight or nursing care. In Vermont, some Level III homes are also designated as Enhanced Residential Care (ERC) providers, meaning they have the capability of accepting some residents needing a

Helpful Hints

- Take a tour of several homes, with your loved one if he or she is able to accompany you and especially if he or she wants to participate in the decision.
- Ask questions about any aspect of the residents' care and daily life. How is the food?
- Ask if you can stay for lunch. Does the home have a special unit for people with dementia? If not, does it have a special activities program? What training have the staff received related to dementia?
- What is the ratio of direct-care staff (not supervisors or office staff) to residents? Does the staff-to-resident ratio meet or exceed state requirements, including coverage for holidays and vacations?
- Are there certain prescribed visiting hours or can you drop in when it is best for you? Do the patient rooms and public areas smell fresh and clean?
- **Use the helpful checklist you can find at www.dail.state.vt.us/lcinfo**

Choosing a Home

When a person's care needs can no longer be met at home, the family and the person face the decision to move to a long-term care facility. The information presented here can be applied to choosing a residential care home or a nursing home. If you, a relative, or a friend has already had experience with the residential or nursing homes in your community, that experience can help you in considering which home is the right one for your loved one. But even without past experience, you can learn a lot during a *preliminary visit*.

Long Term Care Facility Visit

The nursing home visit is probably the most important step in selecting the right home. A visit provides you with an opportunity to talk to staff, and more importantly, with the people who live and receive care there.

When you visit any long term care facility, you will probably be given a formal tour. While this may be a very useful introduction to the home, it is important that you are not overly influenced by a guided tour. When the tour is over, return to some of the places where staff members are caring for residents. Be ready to ask staff members questions about their jobs and how they feel about caring for people with so many different needs.

Near the beginning of your visit, spend time examining the home's most recent survey. Vermont conducts surveys of every nursing home at least once a year. By law, this survey must be posted in an area accessible to visitors and residents. Survey results are also posted on the states' web pages (www.dail.state.vt.us).

When visiting long term care facilities, pay special attention to quality of life issues. People who are admitted to homes do not leave their personalities at the door, nor do they lose their basic human needs for respect, encouragement, and friendliness. All individuals need to retain as much control over the events in their daily lives as possible.

To check to see if the staff respects the dignity of each individual, look into these questions:

- Are staff members courteous to residents and is the home's management responsive to concerns raised by residents?
- Does the home provide a variety of activities and allow residents to choose the activities they want to attend?
- Does the home provide menu choices or prepare special meals at the request of residents? (Sample the food if possible)
- Are family members encouraged to visit, and are they allowed to visit in privacy when requested?



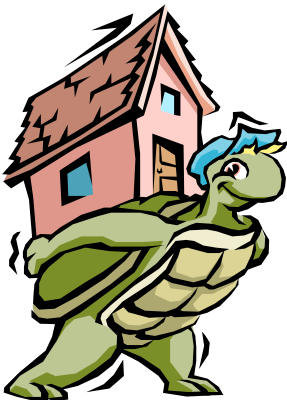
Once you and your family members have chosen the home you think would be best for your loved one, fill out an application and ask about the waiting list and admission process. The staff will ask you some specific questions to confirm that their level of nursing home care is appropriate for your loved one. Check with your loved one's current physician to make sure that he or she will visit in that particular home. If not, ask the doctor

to recommend someone and have the medical records forwarded to the new physician.

The application will require you to identify who will pay the bills. Because Medicare and its supplemental policies pay for very little nursing home care, under very limited circumstances, you or your loved one will need to designate another payment source. Some people entering nursing homes have assets (bank accounts, investments, property, disability insurance) to use to cover the cost of their care. Others will need to apply for Medicaid to help with the expenses. The Medicaid eligibility rules are complicated – plan to get advice about Medicaid well ahead of time. The Alzheimer’s Association of Vermont can refer you to agencies that provide information about Medicaid rules or your attorney can advise you.

Making the Move

When the time comes, your loved one is entitled to know as much as possible about a potential move to residential care or a nursing home. However, when a person with dementia is ready for residential or nursing home placement, he or she has often lost the ability to understand where he or



she is going or why. If possible, discuss the move in terms your loved one is capable of understanding.

When participation in such a discussion is not possible, you may find it helpful to consult with an Alzheimer’s support group or your physician to determine the best way to talk about the move with your loved one.

Pack clothing your loved one is accustomed to wearing and a few favorite possessions for the room, such as a picture, a favorite quilt or blanket (preferably washable), or the wall clock from the living room or bedroom (the familiar ticking may be subconsciously soothing). Label clothing and other possessions with your loved one’s name. Do not send valuables or heirlooms to a residential care or nursing home any more than you would to a hospital.

Ask to meet with someone in charge at the home (preferably a direct-care staff supervisor) so that you can share information about the person's particular preferences and care needs.

Moving day is never easy.

Consider how much time you will spend with your loved one during his or her first day. Remember that eventually he or she will adjust to the new surroundings, and will be comfortable and content.

After the Move

Your loved one may be relieved after the move, since residential care usually means fewer chores and more time for activities.

Good residential and nursing homes welcome family involvement in the planning of care for residents. When your loved one is admitted, you will learn about the special rights home residents have.

They include:

- the right to always be treated with dignity and respect
- the right to make suggestions or complaints without the resident being mistreated or socially ostracized
- the right to consent to or refuse anything (such as food, activities, treatment); in other words, the right to make all one's own decision
- Never hesitate to speak to a supervisor if you want to make suggestions or request changes in the person's care. You can be as involved in the care of your loved one as you desire. If there's a problem that the home administrator cannot or will not resolve, contact the Alzheimer's Association for information on how to report it to the appropriate state oversight agency.

After the move, you will have a lot of time to consider what you have accomplished by your caregiving to this point and what you can do for your loved one and for yourself. You should consider letting yourself get some much-needed rest and allowing yourself time to adjust. Now that you've

been relieved of the round-the-clock demands of caregiving, you may experience a wide range of emotions, including grief, anger, loneliness, guilt, and relief. You may need to express your feelings and to hear the advice of others who have had similar experiences. Family, friends, clergy, a nursing home social worker, and others may help, as may an Alzheimer's support group. When you share the tasks of caregiving with the staff of the nursing home, you will be able to get the rest you need and your time together will be more enjoyable and satisfying.



Louise Moves Her Mom

My name is Louise, and I live in a small town in South Central Illinois. My mother was diagnosed with Alzheimer's eight year ago. The past three years she has been in a nursing home.

We recently moved our mother to a facility that offers an Alzheimer unit with specialized care and a well-trained staff. I cannot emphasize this enough: a well-trained staff. Most nursing homes do not offer the proper kind of training for their staff to be able to deal effectively with an Alzheimer patient.

One of the staff nurses, who we trusted, urged us not to move our mother, that it would be too disruptive for her. But when we heard that the nurse, who's husband has Alzheimer's and is in the same facility as our mother, decided to move him, we thought, why do we have to stay here?

Moving our mother has been her salvation. The exclusiveness of the Alzheimer unit has helped her to start having a better quality of life. If anyone is facing the agonizing decision of placing a parent in a long-term health care facility, I urge you to look for one that offers an Alzheimer's unit of specialized care. In a perfect world, things would go smoothly. But there is no perfect nursing home, but the need to stay proactive in your parents care is vital.

Although the twinkle in her eye is fading, she still smiles and occasionally says a familiar name. We have the confidence that she is being cared for.

A Final Word

Our final word to you is this: take good care of yourself while caring for your loved one with Alzheimer's disease. It will help you to survive and continue living well after your loved one is no longer an active part of your life. You may have made many sacrifices while caring for a loved one with dementia, and now you may make other choices.

Grieve whenever you need to, whether your loved one is still living or has died, and seek out others who understand. You have gained a tremendous amount of experience in dealing with one of the hardest tasks life gives us. Your experience is valuable, and sharing it will not only help other caregivers in the midst of their task, but will also remind you that you are a worthwhile person with skills and knowledge to share.

